

TECHNOLOGY IN REHABILITATION

REPORT OF THE SECOND SYMPOSIUM OF FUNDING ORGANISATIONS SUPPORTING PROGRAMMES FOR DISABLED PEOPLE

4 MARCH 1991
BANGALORE



DISABILITY DIVISION

ActionAid

POST BOX NO. 5406, 3, REST HOUSE ROAD, BANGALORE-560 001
TEL. 564682-83 TELEX: 0845-2142 FAX: 0812-564684 CABLE: ACTIONAID
REGD. H.O. HAMYLN HOUSE, ARCHWAY, LONDON N19 5 PG

Community Health Cell

Library and Information Centre

367, " Srinivasa Nilaya "

Jakkasandra 1st Main,

1st Block, Koramangala,

BANGALORE - 560 034.

Phone - 5501510, 1550555

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**ACTIONAID
1991**

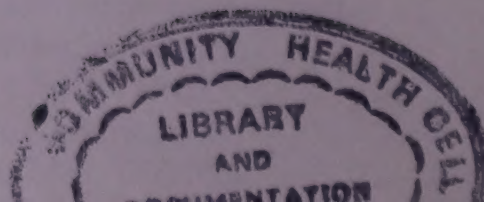
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FOREWORD OF THE FIRST SYMPOSIUM [1990]

The evolution of organised health care in most countries has its origin in curative medicine, leading to preventive medicine and then on to rehabilitation medicine. Many of the developing countries are in various states of this evolution. India is one of the signatories to the Alma Ata Declaration of 1978, and is committed to including rehabilitation services as a part of Health for All by 2000 AD. Rehabilitation received a further fillip with the declaration of 1981 as the International Year of Disabled People and 1983-1992 as the International Decade of Disabled Persons. In many developing countries including India, rehabilitation policies and priorities have been slowly taking shape in the last few years.

According to the World Health Organisation (WHO), about 10 percent of the world's population is disabled in some way. In India, the National Sample Survey of 1981 indicated that about 1.8 percent of the country's population at that time had locomotor, visual and communication disabilities - the three disabilities that were included in the survey. Statistics from other sources show that mental retardation is prevalent in about 2 percent of the country's population. Overall, it can be said that at least 3.8 percent of the population in the country is disabled in some way, which amounts to a significantly large number of people to be taken care of.

In any country, resources to cover a large population of disabled people would be limited, as rehabilitation programmes are cost-intensive. This is more so in the case of developing countries like India. Sources of financial support for rehabilitation programmes may be internal or external. In India the Government and other non-governmental funding sources within the country provide the major internal funding support for rehabilitation programmes. Studies sponsored by the Ministry of Welfare, Government of India in certain states, as quoted by Narasimhan and Mukherjee (1986), show that the financial contribution made by voluntary agencies for the programmes they run is hardly to the tune of 10 percent of their total costs. External support denotes overseas donor organisations.

During the 1980-85 plan period, the Central Welfare Ministry's planned and non-planned expenditure for disability welfare was about Rs. 11 crores per year. Assuming that there were about 20 million disabled people in the country at that time, this amount would have averaged at about Rs. 5.50 per disabled person. Even if the Government spending on rehabilitation were to increase, along with the contributions from voluntary organisations themselves, the gap between needs and resources in cost-intensive rehabilitation programmes would still be wide and need to be addressed through other means. Considering this, along with the magnitude of the

problem of disability, it is apparent that the answer lies in optimal utilisation of available resources.

For the purpose of optimal resource utilisation, the areas requiring greater attention are professional management of rehabilitation programmes, establishment of appropriate service models and trained manpower to meet the rehabilitation needs of the country, ongoing research and repeated evaluations of programmes and continuous dissemination of available data in the field of rehabilitation.

Since all these areas are important, require stringent maintenance of quality at all the levels and may be costly, it may not be possible for a single organisation to develop all of them. The need, therefore, is for pooling of resources, developing strategies for co-ordination and collaboration and avoiding duplication of efforts. During the Tokyo International Congress of Rehabilitation International in 1988, the need for co-ordination among donor agencies in developing countries was one of the issues that was well brought out.

ActionAid is a UK based development organisation, supporting integrated rural development programmes in developing countries in Asia, Africa and Latin America. ActionAid has been working in India since 1973. In 1988, ActionAid-India confirmed the policy of earmarking part of the annual outlay for disability initiatives, which led to the formation of a separate division to deal with projects for disabled people. The disability and rehabilitation programmes supported by ActionAid are long-term ones, ranging from institution based rehabilitation programmes to community based ones.

ActionAid is now moving towards active participation in and contribution to, the National effort in rehabilitation programmes. The time is therefore appropriate to initiate networking and co-ordination of organisations involved in supporting disability initiatives.

The objectives of the symposium were: to initiate a common forum for funding organisations involved in rehabilitation programmes to meet periodically, to share information on each other's activities, to develop possible collaborative ventures in rehabilitation in order to avoid duplication of efforts, and to widen the scope of funding resources in the country.

An attempt was made to enlist the participation of as many donor agencies involved in rehabilitation as possible. The final list of participant organisations included the Government (Central and State), UNICEF, ADD-India, Royal Commonwealth Society for the Blind, Christoffel Blinden Mission, CARITAS-India, German Leprosy Relief Association, ActionAid and Brooke Bond (India) Private Limited.

Though the representation was small, some of the participant organisations like UNICEF are significant contributors to disability initiatives in the country. The notable achievement of the symposium was that it initiated a co-ordinated effort between different donor organisations in the field of rehabilitation, firstly, in the form of a consensus for a common forum to meet every year and secondly, in the agreement on the need for collaboration in service, research and dissemination of information.

The participation in this first meeting was limited to a small number of donor organisations, some of which have large amounts of financial resources at their disposal. It would be desirable to enlarge the scope of such meetings to include many more organisations, including those with limited resources and those for whom disability may not be a priority. When the quantum of funding is small, the impact may be minimal. This can be overcome through

collaboration and co-ordination between organisations in terms of management, technical and funding resources, to achieve greater impact.

What is foreseen for the future are regular meetings and collaboration between different donor organisations - Government, external funding organisations, non-Government and other internal funding sources. The end goal of evolving such a common forum should be to hasten the development of mutually agreed upon collaborative programmes in rehabilitation, with optimal resource utilisation.

26 March 1990.

Dr. Maya Thomas
Disability Division
ActionAid-India
P.B. 2527
Bangalore-560 025

FOREWORD

The first Symposium of Funding Organisations supporting programmes for disabled people was organised by the Disability Division, ActionAid-India, on 26 March 1990 at Bangalore. The objectives were to initiate a common forum for funding organisations involved in rehabilitation programme to meet periodically, to share information on each other's activities, to develop possible collaborative ventures in rehabilitation in order to avoid duplication of efforts, and to widen the scope of funding resources in the country. It was decided during the first Symposium that such meetings should be an annual feature, concentrating on matters of topical interest in the area of rehabilitation. The second Symposium on Technology in Rehabilitation was the sequel, dealing with the development and current status of available technical aids in India, their funding requirements, appropriateness, future trends and dissemination of information regarding these matters.

In India, only 10 to 20 percent of the population of disabled people in need of technical aids are able to get them. There are several reasons for this — the high costs of the aids, the lack of suitability to Indian conditions in some cases, inadequate maintenance and repair facilities, low volume production, lack of adequate marketing and distribution channels, lack of information regarding their availability and so on. Development of low cost and appropriate technical aids has not received much attention in India. There is a need to evolve policies in the field of research and development in the area. With the emergence of biomedical engineering and electronics, along with new materials for technical aids, there is tremendous scope for progress. This is necessary, both to keep pace with developments in the rest of the world and to reach out to the large number of disabled people in the country. There is also the need for closer interactions between the rehabilitation personnel, the biomedical engineers, the manufacturers, the policy makers, the funding sources and the end users of the technical aids — the disabled people, in order to translate laboratory technology to appropriate field level technology, keeping in mind the actual needs of the end user.

Wide dissemination of information about available technical aids is necessary to avoid wastage of resources in inventing, testing and producing similar and often identical, aids. Other bottlenecks that slow down development in this area include lack of established classificatory systems and absence of centres of storage and dissemination of information, among others.

The 1983 recommendation of the International Labour Organisation (ILO) stresses the simultaneous development of technical aids and evolving services. Absence of such simultaneous development, along with an over-dependence on imported aids and lack of indigenously developed aids, can bog down the entire programme of rehabilitation services, leaving little or no impact.

The objective of this year's Symposium was to disseminate information on the current status in the field of technical aids for people with different disabilities, and to provide an orientation to policy makers and others involved in rehabilitation on current priorities in the field of technical aid development in the country. The participants included policy makers, rehabilitation professionals, representatives of service organisations, manufacturers of technical aids, biomedical engineers and users of technical aids. Locomotor, visual and communication disabilities, and mental retardation — the four areas which are current priorities in the country — were dealt with, in terms of current status, existing lacunae and possible future trends with regard to technology. This was followed by discussions and exchange of ideas regarding the needs of the day in the area of technology in rehabilitation.

The issues that were highlighted by the Symposium were continuous information gathering and dissemination, surveys of the magnitude of the problem, promotion of consumer awakening and action, promotion of technology for preventing of disabilities, support to training programmes, proper utilisation and maintenance of technical aids, research on appropriate materials, participatory decision making and a multi-disciplinary approach to technology development in the field of rehabilitation.

It is hoped that this Symposium would provide a further impetus to the development of technology in rehabilitation.

4 March 1991

Dr. Maya Thomas
Disability Division
Action Aid - India
P.B.No. 5406
3 Resthouse Road
Bangalore-560 001.

Technology in Rehabilitation

Second Symposium of Funding Organisations Supporting Programmes for Disabled People

Date : 4 March 1991

Venue : Manpower Development Centre, Unity Buildings, J.C. Road, Bangalore-560 027

Agenda

- 9.00 a.m. - WELCOME AND INTRODUCTION
Dr. Maya Thomas,
Field Director - Disability Projects,
ActionAid-India.
- 9.30 - 10.30 a.m. - I. TECHNOLOGY— BROAD OVERVIEW, RATIONALE AND NEED
Dr. C. M. Francis,
Director, St. Martha's Hospital,
Bangalore.
- 10.30 - 11.00 a.m. - COFFEE BREAK
- 11.00 - 12.00 NOON - II. TECHNOLOGY FOR LOCOMOTOR
DISABILITIES— CURRENT STATUS AND FUTURE
TRENDS FOR POLICIES AND PRIORITIES
Dr. Suranjan Bhattacharji,
Dept. of Physical Medicine and Rehabilitation,
Christian Medical College and Hospital,
Vellore.
- 12.00 - 1.00 p.m. - III. TECHNOLOGY FOR VISUAL DISABILITIES— CURRENT STATUS
AND FUTURE TRENDS FOR POLICIES AND PRIORITIES
Dr. M. S. Ravindra,
Medical Director Lions Eye Hospital and Cornea Grafting Centre,
Bangalore.
- 1.00 - 2.00 p.m. - LUNCH BREAK
- 2.00 - 3.00 p.m. - IV. TECHNOLOGY FOR COMMUNICATION DISABILITIES— CURRENT STATUS
AND FUTURE TRENDS FOR POLICIES AND PRIORITIES
Dr. N. Rathna,
Former Director,
All India Institute of Speech and Hearing,
Mysore.
- 3.00 - 3.30 p.m. - COFFEE BREAK
- 3.30 - 4.30 p.m. - V. TECHNOLOGY FOR MENTAL RETARDATION— CURRENT STATUS
AND FUTURE TRENDS FOR POLICIES AND PRIORITIES
Dr. Shoba Srinath,
Associate Professor & Head,
Unit of Child & Adolescent Psychiatry,
NIMHANS, Bangalore.
- 4.30 - 5.30 p.m. - VI. DISCUSSIONS AND SUMMING UP
Chairperson : Dr. C. M. Francis.

LIST OF SPEAKERS AND PARTICIPANTS

SPEAKERS

- | | |
|--|--|
| <ol style="list-style-type: none"> 1. Dr. C. M. Francis,
Director,
St. Martha's Hospital,
Nrupathunga Road,
Bangalore - 560 009. 2. Dr. Suranjan Bhattacharji,
Dept. of Physical Medicine and Rehabilitation,
Christian Medical College,
Vellore - 632 004. 3. Dr. M. S. Ravindra,
Medical Director,
Bangalore West Lions Eye Hospital & Cornea
Grafting Centre, | <p>56/2, H. Siddaiah Road,
Bangalore - 560 002.</p> <ol style="list-style-type: none"> 4. Dr. N. Rathna,
Former Director,
AIISH,
660, Double Road,
Kuvempu Nagar,
Mysore - 570 023. 5. Dr. Shoba Srinath,
Associate Professor & Head,
Unit of Child & Adolescent Psychiatry,
NIMHANS,
Bangalore - 560 029. |
|--|--|

PARTICIPANTS

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. Mr. N. G. Hegde,
Marketing Executive,
ALIMCO, Limb Centre,
Victoria Hospital, Bangalore - 560 002. 2. Mr. R. S. Hiremath,
Chief Exective,
Flexitron Centre for Handicapped Technology,
114, Kathalipalya,
6th Cross, 6th Block,
Koramangala, Bangalore - 560 034. 3. Mr. Ravi Amur,
Manager,
Bharat Electronics Ltd,
Jalahalli, Bangalore - 560 013. 4. Dr. R. S. Murthy,
Professor and Head, Dept. of Psychiatry,
NIMHANS, Bangalore - 560 029. 5. Dr. G. G. Prabhu,
Professor and Head, Dept. of Clinical Psychology,
NIMHANS, Bangalore - 560 029. 6. Dr. Sathish Girimaji,
Dept. of Psychiatry,
NIMHANS, Bangalore - 560 029. 7. Dr. C. V. Sastry,
829, 13th Main,
3rd Block, Koramangala, Bangalore - 560 034. 8. Mr. S. L. Desai,
631, 5th Main, 2nd Stage,
Indiranagar, Bangalore - 560 038. | <ol style="list-style-type: none"> 9. Dr. T. Murali
Dept. of Rehabilitation,
NIMHANS, Bangalore - 560 029. 10. Dr. Julius Karunakaran,
Area Representative,
Christoffel Blindenmission,
1, Highways Colony, Tiruchirapalli - 620 020. 11. Mr. G. J. Yesudian,
CSI Council for Child Care,
50, Lavelle Road, Bangalore - 560 001. 12. Mr. Austin Saji,
CSI Council for Child Care,
50, Lavelle Road, Bangalore - 560 001. 13. Ms. Mary Roodkowsky,
Project Officer,
Nutrition and Child Disability,
UNICEF, 73 Lodi Estate,
New Delhi - 110 003. 14. Mr. S. Venkatakrishnaiah,
Assistant Director,
Directorate of Disabled welfare,
Ground Floor, Podium Block,
Visveswarayya Tower, Dr. Ambedkar Veedhi,
Bangalore - 560 001 15. Mr. M. S. S. Varadan,
Managing Director,
Om Consultants (I) Pvt Ltd.
P. B. No. 356, 9th Cross,
6th Main, Malleswaram, Bangalore - 560 003. |
|---|---|

16. Mr. R. Sridhar,
Om Consultants (I) Pvt. Ltd
P. B. No. 356, 9th Cross,
6th Main, Malleswaram, Bangalore - 560 003.
17. Mr. N. C. Bose Croos,
Worth Trust,
48, New Thiruvallam Road,
Katpadi - 632 007, Tamil Nadu.
18. Dr. S. Nikam
Incharge Director,
All India Institute of Speech & Hearing,
Manasagangotri, Mysore - 570 006
19. Mr. S. A. Khan,
Director.,
Hyderabad Science Society,
12-2-460, Mehdiapatnam, Hyderabad - 500 028.
20. Ms. C. K. Meena,
Deccan Herald,
Mahatma Gandhi Road, Bangalore - 560 001.
21. Mr G. R. Srinivasan,
Rehabilitation Officer ,
German Leprosy Relief Assn.
Rehabilitation Fund,
4, Gajapathy Street,
Shenoy Nagar, Madras - 600 030.
22. Dr. M.J. Thomas,
Consultant Psychiatrist,
MEDINOVA,
55, Infantry Road, Bangalore-560 001.
23. Prof. T. G. Krishnamurthy,
24, Shanthi Kutir,
15th Cross, Malleswaram, Bangalore-560 003.
24. Mr. Marc Bonnet,
Programme Director,
Handicap International India,
38, 3rd Cross, Colas Nagar,
Pondicherry - 605 001 (TN).
25. Mr. M. P. Srinivasan,
Principal Research Scientist,
Indian Institute of Science,
Bangalore-560 012.
26. Mr. B. Venkatesh,
Executive Director,
ADD - India,
P B No. 2598, Bangalore-560 025.
27. Mr. Sampath Kumar,
Karnataka State Council
for Science & Technology,
Indian Institute of Science Campus,
Bangalore-560 012.
28. Dr. T. V. Ananthapadmanabha,
Chief Executive,
Voice & Speech Systems,
53, Girinivas, 13th Cross,
Temple Street, Malleswaram,
Bangalore-560 003.
29. Prof. S Jeevanandam,
Madras Christian College,
Tambaram, Madras.
30. Bro. Anand,
Gandhi Rural Rehabilitation
Centre,
Alampundi, Gingee Taluk,
S.A. Dist-604 151 (T.N.)
31. Mr. S. Kumar,
Gandhi Rural Rehabilitation Centre,
Alampundi, Gingee Taluk,
S.A. Dist-604 151 (T.N.)
32. Mrs. Bhargavi Nagaraja,
11, Uttaradi Mutt Road,
Basavanagudi, Bangalore-560 011.
33. Mr. Ravi Narayanan,
Executive Director,
ActionAid, P B No. 5406,
3, Resthouse Road,
Bangalore-560 001.
34. Ms. Smitha Premchander,
Programme Field Director,
ActionAid, P B No. 5406,
3, Resthouse Road,
Bangalore-560 001.
35. Dr. Maya Thomas,
Field Director, Disability Division,
ActionAid, P B No. 5406,
3, Resthouse Road,
Bangalore-560 001.
36. Mr. Joseph Panackel,
Programme Officer, Disability Division,
ActionAid, P B No. 5460,
3, Resthouse Road,
Bangalore-560 001.
37. Ms. Christy Daniel,
Programme Officer,
Disability Division,
ActionAid, P B No. 5406,
3, Resthouse Road,
Bangalore-560 001.

Technology in Rehabilitation

Dr. C. M. FRANCIS

"Do not pity me. Let me be like others. I want to walk; I want to see; I want to hear; I want ...". This is the cry of people with disabilities.

Disabled people want to be able to do things like others in the society. Can they be enabled to help themselves? Can we help them to manage better at home, in the school, at the work place and in the community? Can we reach out to help them to overcome their handicaps?

Technology can help to make people return to ability. Giant strides are being made in technology, bringing the fruits of science to humanity. Unfortunately, the application of technology in rehabilitation has been slow and often irrelevant and inappropriate. Technology often does not have a human face (Small is beautiful - E. F. Schumacher).

Rehabilitation should aim at the total person, so that he/she can have a useful, productive life, can be gainfully employed, can contribute to society, can be in harmony with himself/herself, the family, the community and the environment, and have an acceptable level of Quality of Life.

One area of technological progress neglected by people involved in rehabilitation is **prevention**. The benefits are enormous, the dividends are large and it is most cost effective.

We will soon be reaping the benefits of **immunization** by polio vaccine. The science of immunology has been put to use by the advanced technology of production of the vaccine and the simple technology of distribution (cold chain) and universal use. Polio can be eradicated through effective immunization. A major cause of locomotor disability in our country will thus disappear and the orthopaedic surgeons will have to find other avenues of service.

Other preventable causes of disabilities are accidents on the roads, at the workplace and elsewhere; excessive noise causing deafness, vitamin A deficiency causing blindness, iodine deficiency diseases, injuries during sports and games, unsafe toys and birth injuries. The technology to prevent them exists and we must learn to use them.

If we could not or did not prevent disabilities, we can **extend abilities**. There is a plasticity of the body which makes it adaptable. The different parts can substitute for the missing functions. People without hands draw and paint with their feet or the mouth producing beautiful paintings.

Surgical and medical procedures can extend the abilities. Lens implants for vision, cochlear implants for hearing, joint replacements and host of other surgical procedures have been developed and put to use. Behavioural therapy can also be useful. Physiotherapy and occupational therapy have

been extensively used to increase the abilities of disabled people.

If it is not possible to overcome the handicaps (or reduce them) by medical, surgical or other means, **aids and appliances** can help. It is important that the aids and appliances conform to certain requirements:

1. Is it feasible within the resources of commonly available technology, finances, materials and other considerations?
2. Is the technology simple enough to be understood and used?
3. Is it acceptable to the user, the family and the community?
4. Is it flexible, so that it can be used under different circumstances and needs?
5. Are the parts interchangeable, so that if a part goes out of order, it can be replaced easily?
6. Is it portable? Can it be used at home, in the school, in the workplace, on the road?
7. Can the user, the family and the society afford it? Spread spectrum switches can be held in the hand and operated but the cost may be beyond the reach of the person.
8. Is the appliance durable?
9. Can the appliance be serviced without difficulty, if possible by the user, or at least in the locality?

The aids and appliances may be for many different purposes, such as personal care, household work, learning, use in work, locomotion, transportation, communication, vision, hearing and leisure-time.

Training of disabled people is very important to enable them to use their other faculties, or to adapt them, or to use the aids and appliances optimally. Such training may be individual or in groups (in specialised schools or in ordinary regular schools). The technology of training must be appropriate. There are many improved techniques of learning and teaching, appropriate to the person concerned. There are many teaching aids and methods of communication to facilitate learning. An important consideration is to ensure that the person is able to continue to use the learning methods, even after the formal learning has been discontinued.

Often, we can use technology to bring in **changes in the environment** to enable the disabled person to live and work better. In many countries, there is legislation requiring buildings to be barrier free giving access to people. The

furniture and gadgets in the home can also be such that the person can move around and use them without difficulty. In developed countries there are regulations by which persons with disabilities can cross the roads safely. Our country however, has a long way to go before we reach similar standards of concern for rehabilitation of disabled people.

Very little is being done in our country by way of **research** into the problems of disabled people, their causes and effects. People say "we are not able to look into the problems of the able-bodied. How can we think of the disabled?" The answer is that each person, able-bodied or disabled, is a human being entitled to the same rights. Yet again people ask: "Why should we do research. Other countries who can afford it are doing research? We can use their results". The fact is that the research done elsewhere, especially in the affluent countries, is often irrelevant here. We are different economically, culturally and otherwise. What is affordable

and acceptable elsewhere need not be so in India. We have to do our homework. There are many areas where research is needed. These include the appropriate technologies of diagnosis, management and prevention. We have to adapt the technology available to us. This may include the use of electronics and simpler computers. India is fast advancing in these areas and if the technology is useful and cost-effective, it will not be proper to deny the benefits to disabled people.

India is placing greater emphasis on primary health care. This is comprehensive and includes rehabilitative care. The technology in rehabilitation must be integrated with all other aspects of primary health care. Use of appropriate technology in rehabilitation can improve tremendously the quality of life of those persons who were born with or have acquired disabilities. ■

Technology for Locomotor Disabilities

Dr. SURANJAN BHATTACHARJI

Introduction

Locomotion is for moving from one place to another — to go to the window to gaze at the stars, to walk down a road to meet a friend, to walk around the shops in the bazaar. Locomotion or walking is for enjoying from one day to another — to play hopscotch, to skip, to run through the park, to meet the child returning from school. It is very important for meeting the world, for growing up, for retreating to solitude, for returning to join again, for carrying out the day's tasks, for belonging. Walking makes a big difference in how one's life turns out, in whether one has a life at all, so it is very important for almost every thing like breathing. In an ideal world, every individual would be able to achieve his or her fullest potential. Unfortunately in this imperfect world of ours there are many impediments which prevent the achievement of this ideal. Let us look at the problem of physical disability which results in locomotor handicaps among our people.

The Problem

The commonest **cause** of locomotor disability in children in our country is poliomyelitis. Other causes are cerebral palsy, congenital defects of the limbs or spinal cord etc. In adults, additional causes are Leprosy, amputations, chronic arthritis, strokes (causing hemiplegia) and spinal cord lesions.

The **numbers** of physically disabled people in our country are variously quoted by WHO, UNICEF and others as being as high as 10 percent of the population. In studies done in Vanyambadi block by the Community Health Department of our Medical College, it was found that 1 percent of the population had a physical disability. Of the disabled population, 40 percent had a locomotor disability. In terms of numbers this is an enormous group and there are probably 3 million persons in our country with a locomotor handicap.

In contrast to this large disabled population, the number of health profession. Is available to treat them is tiny. Each year we train more than 10,000 each of nurses, pharmacists and doctors in our country. However, the number of Occupational Therapists, Physiotherapists and Orthotists-Prosthetists trained per year is probably less than 100. There are less than a dozen medical colleges in the country with departments set apart for the meeting of this enormous need.

Currently available solutions

Although the problem as outlined above is huge, it is heartening to note that a significant amount of work has already been done to address these issues.

Primary prevention

The commonest cause for locomotor disability

— Poliomyelitis — is a preventible infection by a virus. Unlike in the west, Polio eradication has not been successful in our country because of several reasons — the difficulty in maintaining the integrity of the cold chain, poor potency of the live virus vaccine, competing enteroviruses in the gut which prevent the multiplication of the vaccine virus, etc. These problems are, however, surmountable and the Department of Virology at Christian Medical college, Vellore, under the leadership of Dr. Jacob T. John has shown that in Vellore town the incidence of poliomyelitis has been reduced by 90 percent during the past 36 months. Similarly, in Vanyambadi block served by the Community Health department of our Medical College, the improvement of the antenatal coverage and child delivery practice has been associated by a marked reduction in the incidence of cerebral palsy secondary to birth trauma.

Disability Limitation

The basis of disability limitation is early diagnosis and efficient management. To go back to our earlier model of Poliomyelitis, the fact that paralysis is more severe if the child has an injection during the acute phase of paralytic Polio is well documented. When a child is first brought to a clinic with fever, avoiding injections unless there is a life threatening emergency minimizes the chances of a residual paralysis.

Another common example of efficient early management is immediate post-operative prosthetic fitting. The traditional method of management of an amputee is to fit him with an artificial limb three to six months after the amputation when the stump has "matured". This meant that such a patient would often be away from work for a year. Good amputation rehabilitation practice now involves choosing the appropriate patient for fitting of a temporary pylon and mobilisation of the patient on his stump the day after amputation surgery. The definitive prosthesis can be fitted within two to three weeks and the patient can return to work within a month instead of a year.

The third example is the dramatic improvement in the management of Leprosy. Early diagnosis and treatment with the multi-drug regime is now resulting in a marked reduction in the nerve damage and deformities that were so common in patients with Leprosy.

Disability Management

The best example of locally developed and refined technology for the management of disabled people is the example of the Jaipur foot, conceived and developed by a visionary — Dr. P.K. Sethi. Twenty five years ago, he was struck by the high rejection rate of the conventional SACH

foot, the then acceptable solution for amputees. As the SACH foot was designed for a "shoe wearing, chair sitting culture" (terms coined by Dr. P.K. Sethi), the amputee was forced to wear a shoe all the time — an unacceptable burden for someone who normally goes about barefoot and sits and works on the floor. Dr. Sethi then embarked on designing a rubber foot that would not require a shoe to walk in, that would be tolerant to wetting and allow the user to squat and sit crosslegged. Without sophisticated equipment, using only locally available materials and dedicated and skilled artisans he achieved what was thought to be an impossible dream: a rubber foot was designed and perfected that was not only better i.e. biomechanically more suited to the floor sitting life style of our people and the uneven terrain that has to be negotiated, but also cheaper and could be made locally. Since then, the Jaipur foot has been tested in the fire of our varied and rugged environment by thousands of amputees and has been demonstrated to be one of the most outstanding contributions ever made in the field of amputee rehabilitation in our country and perhaps the world.

Another example of an innovative solution developed in response to a local need is the work done by Dr. Paul Brand for Leprosy patients in Vellore. He came to India in the late forties, a young surgeon from England, trained in the reconstruction of hands injured in the second World War. One of the problems that he was confronted with in Vellore was the claw-hand of the Leprosy patient. Not only was this an ugly stigma of the disease, but the deformity rendered the hand useless for activities of daily living. Dr. Paul Brand put his heart and mind to the problem and devised operations that not only corrected the deformities but restored function enabling the patient to earn a living and become a contributing member of society once again. He then turned to the problem of deformed feet and devised operations that shifted tendons to replace the functions of paralysed muscles. For the anaesthetic feet of these patients who are susceptible to recurrent trauma and ulceration, he mooted the idea of using microcellular rubber for the insole to distribute the forces over as large an area of the sole as possible and using pieces of discarded automobile tyres as strong, wear resistant and cheap outer soles. This seminal work started by Dr. Paul Brand has been extended, developed and improved by innumerable others and much more is now known and understood about problems of the disabled leprosy patients.

Another outstanding example of innovation is again that of Dr. P.K. Sethi. He was looking for an alternative solution to the metal and leather calipers which enable a child with a paralysed limb to walk. These heavy appliances were so uncomfortable that children could not wait to take them off. Elsewhere in the world newer materials were being tried out to replace the metal which had served so well for so many years but which had a tyranny of its own. Dr. R.G. Kumble, Advisor, Department of Science and Technology (DST) of the Government of India was the guiding spirit of the "newer

fibres and composites" section — a thrust area in DST. A chance meeting between Dr. Sethi and Dr. Kumble sparked off a partnership which resulted in the development of the Carbon-fibre floor-reaction-orthosis. This appliance, suitable for polio patients with a quadriceps paralysis had been conceived by Saltiel in Israel in the seventies but was developed and adapted for children in India by Dr. Sethi. It has several advantages over the traditional brace: the person using it can flex his knee during the swing phase of walking; the weight of the C-fibre brace is a fraction of the weight of the metal caliper and instead of being tied down to the heavy orthopaedic shoe which is an essential part of metal calipers, the user can choose whatever footwear he wishes to use. In addition, this orthosis made from a space age material is not more expensive than the traditional caliper.

Dissemination of Available Technology

The successes like the dramatic improvement in the treatment of leprosy need to be widely known so that patients will cease to be afraid of presenting themselves with early symptoms for diagnosis and treatment. Polio prevention on a large scale has already been adopted by the Rotary International, the Indian Government and others as a desirable and achievable goal. Knowledge about the ill effects of injections in acute poliomyelitis needs to be spread but more importantly, the pernicious practice of giving injections as panaceas for all ailments needs to be changed — particularly when a child is brought with fever. The Jaipur foot though widely accepted throughout the world as an excellent option, is not available as an option for many amputees in our country. We need to examine this carefully — it is easy to ignore the local solutions only because they happen to be local. The imported, expensive solutions have a glamour that can be blinding. There is also the danger of not implementing the "good" because we are searching for the "best". The search for better solutions must go on hand in hand with implementation of available solutions. This implies a certain flexibility in the mechanisms available for supplying appliances and devices for disabled people so that the patient is not squeezed into an appliance but the appliance is tailored to suit his requirement. We need to work towards changing the system so that an appliance is not dictated or thrust on a person from a distant centralised authority but the informed patient and his team of professionals can together choose what would be the best from several options.

There have been several attempts at "upgrading" successful local programmes to cover larger areas and these have not always been successful. This is not surprising as the forces acting in locally successful solutions are not always available on the "national" scale. In engineering, after a product has been developed in the laboratory and tested and proved in the field, a lot of work needs to be done to determine new processes that would be useful in the scaling up of production from a laboratory model to an industrial one. Similarly, perhaps

it is wrong for us to assume that a rehabilitation model that has been highly successful in a local setting will necessarily be successful when implemented without changes, on a wider scale.

In order to disseminate the available technology, the lack of sufficient numbers of trained personnel (physiotherapists, occupational therapists, orthotists and prosthetists, engineers and doctors) is a problem that must be addressed. The traditional solution of starting more training courses to make up for the lack of numbers is merely one of many possible. Unconventional solutions like that demonstrated by Dr. Sethi should not only be encouraged but actively assisted. Community Based Rehabilitation (CBR) has already been shown to be a more viable solution to the enormous problem of delivering rehabilitation services to the rural disabled. Training of multipurpose rehabilitation workers for these community based programmes is an important challenge as is the development of suitable mechanisms to ensure that the appliances can be repaired locally when worn out or broken.

Development of Newer Technology

The thrust for newer technology must surely be multifaceted. Some areas that seem particularly useful are:

Improved surgical techniques and instrumentation for operations on the limbs and central and peripheral nervous system for restoration of function. The development of microvascular surgical techniques has opened the door for composite tissue transfers that can potentially revolutionize reconstructive surgery for locomotor disabilities just as it has revolutionized surgery for other problems like reconstruction after cancer surgery.

Composites: Human civilization has passed through the stone age, the bronze age, the iron age etc. The modern day has been hailed as the nuclear age or the space age. Perhaps another name could be the Plastic age. Plastics in general, and composites of fibre reinforced plastics in particular have transformed our lives because not only can one now design a structure according to one's needs, one can even design and engineer materials to have the characteristics most suited for the task. The dream of the alchemists is really becoming true. Research needs to be done as to how best these advances can be harnessed for the use of those with locomotor disability. Thermoplastics, rather than thermosets, with their potential for remoulding after trial on a patient seems to hold particular promise for calipers and braces. Carbon fibre reinforced composites show great promise for "energy releasing" foot pieces for lower limb amputees. Polyurethanes with their versatile properties are being tried

out as inserts for the Jaipur foot as well as for a wear resistant "skin" and sole.

Joint Replacement Surgery: Joint replacement surgery in our country has remained a luxury that only the rich can afford because the implants have to be imported. We owe it to the large number of patients who suffer from chronic disabling arthritis in our country to develop the technology and production capabilities of high quality artificial joints. Use of newer materials like ceramics and special alloys in joints designed for squatting and sitting cross legged could help transform the lives of thousands of disabled people.

Functional Electrical Stimulations: Several of the disabilities listed earlier like cerebral palsy and hemiplegia, leave an intact motor unit. The afflicted person has however, lost the ability to control these motor units. In these situations, Functional Electrical Stimulation or stimulation of the desired motor units by external or internal artificial electrical appliances seems to hold promise. Pacemakers for hearts with rhythm defects have been used for many years now. The rapid advances in microprocessors and control systems need to be translated into devices that can reliably be used by people with locomotor disabilities.

The Department of Physical Medicine and Rehabilitation of Christian Medical College, Vellore, has inherited a tradition of treatment of paraplegic patients from Dr. Mary Verghese who founded this department twenty six years ago. Thanks to the generosity of the Department of Science and Technology, we have been funded for a joint project with Dr. N. G. Nair, Head of the Fibre Reinforced Plastics Centre of the Indian Institute of Technology, Madras. We are exploring the use of plastics for mobility aids in this group of severely disabled individuals. We are working on the design and development of better calipers, wheelchairs and tricycles. In order to objectively assess our efforts at helping patients with locomotor disabilities, we are in the process of setting up a gait analysis laboratory with facilities for 3-D motion analysis. I believe that for technology to become useful for disabled people, there needs to be a very close interaction between disabled people, the members of the traditional health team and members of the engineering sciences. The setting up and nurture of such multidisciplinary groups is probably one of the most urgent priorities that needs to be addressed.

In conclusion, locomotion makes a big difference in how one's life turns out... in whether one has a life at all. And so, though it is expensive in terms of human endeavour, it is essential that we invest in a future where as many as possible of our people are enabled to walk. ■

Technology For Visual Disabilities

Dr. M. S. RAVINDRA.

Eighty percent of the knowledge which the human brain gains is through the eyes, which indicates how important the sense of vision is for people to carry on their daily activities. The eye is the medium wherein the light energy is converted to electrical energy, which is conducted to the brain, and thus what is seen is analysed.

It is estimated that there are about 10.21 million blind people in the country. The main causes of visual disability are cataract and corneal opacity. A nation-wide survey by the National Programme on Control of Blindness has established that cataract causes 81 percent of blindness in India. The survey has also indicated that the onset of visual disability is predominately after the age of 45 years. In developed countries, the onset of cataract is usually after the age of 60 years but in India, because of the high amount of ultra-violet light, the lens of the eye tends to become cloudy much earlier. Thus an average individual starts developing cataract by about 45-50 years and most people undergo surgery by about 55-60 years.

The treatment for cataract, which is opacity of the lens of the eye, involves a simple surgery, which has undergone many technological changes since it was first performed in 1875. A person who undergoes this surgery has the lens removed from the eye, which leads to loss of focusing power. To rectify this, thick spectacles are provided. These spectacles have the disadvantage of inducing unwanted magnification and reducing the field of vision. The normal range of the field of vision is 150° which gets reduced to 40° - 50° after a cataract surgery. This becomes a limitation and a constraint for mobility. To avoid this, the technique of replacing the cataractous lens of the eye with an intra-ocular lens was introduced in 1950, followed by the re-introduction of modern extra-capsular cataract surgery in 1965. Another innovation in cataract surgery is that a person does not have to wait till he becomes totally blind, i.e. till the cataract matures. There have been tremendous advances in technology related to this surgery, with regard to operating microscopes, very fine needles, finer sutures and above all, better understanding of the eye. The current trend with regard to intra-ocular lens implantation is the multifocal lens, which has the capability of focusing near as well as distant objects. This, however, is still under trial.

The Bangalore West Lions Eye Hospital is deeply involved in all aspects of ophthalmic care, including running an eye hospital with out-patient and in-patient departments; a department of orientation and mobility and low vision aids; prophylactic programmes with screening of school children; a rural programme of eye camps; a modern and successful eye bank and various teaching and research activities.

We have worked extensively to reduce the cost of ophthalmic

surgery in every possible way. Unless the cost factor is kept in mind, it is not possible to conduct around 800 surgeries every month as we do in the rural areas, with a limited budget.

Whatever surgery is done, the objective is to make the patient ambulatory as soon as possible after surgery in the eye camps conducted by the hospital. All efforts are directed at using less expensive, easily and locally available materials. For example, we use the ordinary cellophane tape to bandage the eye after surgery instead of sticking plaster, which may cause allergy and is painful to peel off, especially on the facial skin. In conducting a rural camp, we carry all the equipment necessary for surgery, including all O.T linen, surgical instruments, a kerosene generator, a fire extinguisher and even dustbins. All that is expected from the local area is food for the patients, staff and the volunteer work force. A makeshift operation theatre is created in an existing building such as a school, with a pukka wall and roof. The room is fumigated and lime-washed a week before, and made dust-proof 2 days before the surgeries. Instead of autoclaves, pressure cookers are used to sterilise all instruments. The advantages are that the pressure cookers are cheaper, portable, reliable and easily replaced when in need of repair.

More than 15,000 surgeries have been performed in the last 2 to 3 years in rural areas. There have been no casualties and the success rate is very high. Wound related complications were seen often before we adopted the new techniques but they are almost nil now. The infection rate has come down to a level acceptable in a modern urban hospital. All patients are discharged from the camp 4 days after surgery and re-examined about one and a half months later to disburse appropriate spectacles.

One of the diseases which is very common, often missed by medical personnel and treated wrongly especially in children, is the Dry Eye Syndrome. In this condition, the tear layer on the surface of the eye, which is usually wet, becomes deficient either in quantity or quality. It is a newly recognised clinical entity, which is being given much importance now. Almost one out of 10 patients seen in an eye hospital suffers from this condition. The patient usually complains of grittiness in the eye. It has been found that long term use of antihistamines (for allergic conditions), deworming medicines and anaesthetics can produce the Dry Eye Syndrome, in addition to other causes. Once this condition starts it becomes very difficult to manage and the patient will continue to have the problem for a long time. Much research is needed on the causes, treatment and management of this condition of deficiency in tear fluid.

Nutritional deficiency, especially of vitamin A and proteins,

can cause blindness. Millions of people suffer from this despite the free dispensation of vitamin A supplements. Deficiency is often seen in diarrhoea and worm infestations, which if neglected can result in loss of eyesight in children. Vitamin A deficiency produces night blindness, but not all cases of night blindness are due to this deficiency. There are a number of other causes for this condition and it is wrong to prescribe Vitamin A to every person suffering from night blindness. Vitamin A is toxic and should not be dispensed indiscriminately, especially for adults. Vitamin A deficiency can also cause corneal ulcer, keratomalacia and opacity, due to loss of transparency of the outermost layer of the eye. Unless treated energetically, permanent blindness is inevitable.

Injury is another common cause of corneal opacity, especially in children. Many of the toys and playthings available in the market are not safe, as they have sharp corners which can injure the eye. It is important for parents to realise that such potentially harmful objects must be kept out of the reach of children. Following the telecasting of the 2 Epics, namely Ramayana and Mahabharat, many children suffered eye injuries because of their play with arrows. Industrial workers are another class of people who are prone to eye injuries because of absence of safety glasses and lack of adequate protection for the eyes in potentially hazardous industrial environments.

Congenital diseases can also produce blindness, especially in families with consanguineous marriages.

The Lions Eye Hospital has been active in launching a massive propaganda for eye donations and carrying out corneal transplants. A major campaign to spread the message of eye donation has been undertaken. Techniques to master the graft surgery are perfected and the success rates are now between 80 percent and 90 percent. In some instances where the front of the eye is badly damaged, the only answer is to fix an artificial cornea. Various models are available and the Hospital is also trying to develop its own model of artificial cornea.

Glaucoma is a disease where the pressure in the eye increases and slowly damages the optic nerve, causing gradually progressive blindness. Early detection is important, since the loss of sight is irreversible. It is recommended that all people aged 40 and above should undergo regular eye checks. Many times a patient with Glaucoma is unaware of this condition or thinks he has a cataract and loses valuable time before treatment is initiated. Early screening and timely diagnosis are important here, especially with regard to the population at risk, such as all relatives of patients with diabetes or Glaucoma.

Diabetes is another disease which can harm the retina by

affecting micro blood vessels and resulting in bleeding inside the eye. It is essential for patients with diabetes to undergo yearly eye checks.

A new technological advance in ophthalmic care is the LASER. LASER stands for Light Amplification by Stimulated Emission of Radiation. We know of the laser being used in the military field for destructive purposes. If even one thousandth of the money directed for military purposes is brought in for purposes of medical technology, the number of blind people all over the world could be dramatically reduced. Most of the people who need laser treatment are diabetics and elderly people, of whom at least 70-80 percent are from economically underprivileged rural areas without paying power. Apart from diabetes, laser is also indicated in the treatment of Glaucoma. The most common laser used today is the Argon laser, which was introduced in 1968. The Diode laser is currently in the market, though it is not yet available in our country. The Nd-YAG laser is used to make holes in the thick membranes of the eye, like in cases where a thin layer called "after-cataract" grows inside the eye, causing blindness.

The surgery to correct myopia, which is widely performed in USSR, is called Myopia Surgery or Radial Keratotomy. Several incisions are made with a diamond knife to flatten the cornea and correct the myopia. There are controversies surrounding this surgical technique. In Myopia, the basic defect is that the eye is longer, but the cornea is penalised in this surgery to correct the fault. To replace the incision by the diamond knife, we now have the latest laser called the EXCIMER laser, which costs around 1 crore of rupees. This latest state of the art technology can be used to sculpt the cornea and even remove corneal opacities. The day may not be far when a myopic person can walk in, sit in front of the machine, get something done to his eye and walk out seeing everything clearly again. Many surgeries can be avoided by the use of the laser.

Many of the technological advances that are currently available to visually disabled people in the world remain inaccessible to people in India because of high costs and lack of interest in medical and biotechnology. Besides, the market for such technology remains poorly developed, discouraging those interested in the area from getting into it in a big way. In the recent past, however, many of the sophisticated ophthalmic gadgets have been allowed to be imported free of customs duty by the Government of India. With the establishment of many excellent teaching centres, the technology and skills available in the country today to manage every kind of ophthalmic disorder is on par with any developed country. ■

Technology for Communication Disabilities

Dr. N. RATHNA

A recent visit to several schools for children with hearing impairment and those with mental retardation in different parts of the country revealed an utter absence of the use of educational technology, to the extent that the use of a black board in some places seemed to demand a compliment. On the other hand, some children with communication disabilities in India have access to cochlear implants, F.M. hearing aids, individual hearing aids matched by computers to their hearing losses, speech synthesized communication systems and computer aided instruction materials. In some places, love, dedication and concerted efforts have proved effective rehabilitators of children with hearing disabilities even without the help of hi-tech aids. Many institutions in other developing countries do not have the equipment and library facilities that are available to training institutions in India. The training received by students here has stood up well to the demands of advanced study abroad.

These experiences serve to emphasise that technological aids and sophisticated use of them must be seen only as aids and not as essential prerequisites for adequate rehabilitation. India provides scope for a variety of technological aids suited not just to the terrains, the cultural ethos of technology orientation and the production and maintenance ability, but also to the differing needs of individuals in different regions and at different times. A majority of hearing impaired people in India do not need at present to use telephones, indicating that better hearing aids would take on a higher priority than telephone amplifiers, which in turn would obviously be of higher priority than stethoscope amplifiers. Loop induction amplification of T.V. sound is a greater need than captioned T.V. considering the great magnitude of illiteracy in the country. It must however be stressed that no technological advancement or aid would be superfluous just because only a very small percentage of people with communication disability could use it. Just one percent of 900 million is 9 million people. Thus the need of those with communication disability or any disability varies over a wide range of sophistication and demands, from better black boards and better pieces of chalk to the most up-to-date equipment used anywhere for rehabilitation and research, because there are users for the whole gamut.

There is a great need for a variety of technological aids. Professionals, policy makers and producers have been aware of this and many committees and workshops have tried to identify these needs and to prioritise them. One recent exercise led to the list of needs identified as immediate by the Science and Technology projects in Mission Mode on Application of Technology for the Welfare and Rehabilitation of the Handicapped. The scientists of India have shown their abilities here and abroad in various areas of very advanced science. However, the progress made either in improvement of the

existing aids and their use or in the development of new and modified aids has been disheartening.

The major obstacle to our progress in this direction is a basic absence of a culture of technology and a culture of consideration for others. A look at other countries which are developed in terms of technological aids for disabled people seems to show the following:

- (a) A deep sense of consideration and respect for the other being and his individuality.
- (b) A belief and a faith in his right to a better living.
- (c) An awareness that "apparent increased expenditure" now actually saves in the long run by shortening the "dependency period" and by limiting "dependency areas of activity".
- (d) An ability to spare immediate funds (without which one may feel like some of us who pay taxes because we cannot save enough to avoid taxes).
- (e) A strong "culture of technology" supported by good information technology which permits an exchange of ideas and techniques, along with a respect for results as greater than the sources of those results.
- (f) The accessibility of scientific advances to rehabilitative endeavours as in the case of computer based technology which saved labour, speeded up activity and led to new approaches to rehabilitation techniques.
- (g) The quick interaction that the culture of technology encourages between the researcher and the field applications.

As a contrast to this, the professional, the manufacturer/producer and the user seem to be lacking in this culture or technology and the culture of consideration in our country.

The professional is often so strongly entrenched in his seat of 'Power' that he has no regard for the needs of the clients. Many refuse to help the client because he cannot pay. Sometimes this indifference insidiously grows to the extent of reducing the professional expertise. All of us know the importance of care in selecting hearing aids and the need to match the aid to the needs of the particular client. However, except for a few people we do not get aided audiograms and matched hearing aids even when equipment is available. There are times when equipment is earmarked for some future research and hence is not used for testing or giving therapy. It must also be conceded that many therapy centres do not have the necessary equipment or infrastructure to follow systematic procedures.

We are similarly aware of the importance of proper ear moulds and continued maintenance of hearing aids, but our

efforts at increasing the facilities for these are very limited. When it was suggested that all agencies distributing hearing aids must be forced to provide custom made ear moulds, a policy maker said that this would be difficult because ear mould curing flasks had to be imported. Hundreds of hearing aids are being given every year without proper ear moulds. Many schools for children with hearing impairment have group hearing aids which have not been put to use for want of maintenance. The first attempted public use of an induction loop to help hearing aid users is the recent Ali Yavar Jung National Institute for Hearing Handicapped (AYJNHH) attempt of putting an induction loop in a railway enquiry booth. Very few tape recorders are used in speech therapy around the country though Speech Pathologists keep asking for more and more expensive tape recorders. Many of us go through great effort to persuade our bosses to provide equipment or to build special facilities but when we succeed we have problems giving the specifications or proper advice on how to build the facilities.

Often, the stress on "perfectionism" which is commonly seen leads to a "do nothingism" because nothing can be perfect. This kind of intransigence has come in the way of development of indigenous technology. Two extreme points of view are usually encountered. There are those who insist on only imported equipment inspite of many experiences of such equipment lying unused for want of maintenance or want of spares, sometimes damaged in transit. Occasionally they have not known how to use the equipment in the absence of proper manuals. For these people, if it is foreign it is good and necessary for us, though the sense of acquisition is not always coupled with the ability to fully utilise what is acquired. Many libraries have books "never read". And many computers have been used only as word processors. On the other hand, there are others who want no imports and that is not always for economic reasons. For them anything foreign cannot be used here. They would like to develop their own even when they do not have the infrastructure. The attempts to develop everything can be costly and may also fail. Neither of these attitudes is conducive to the development of indigenous technology.

An important component of the culture of technology is a positive interaction among professionals, manufacturers, users and the clients, which is often lacking here. There is no adequate communication for example, between the hearing aid manufacturers, the audiologist, the otolaryngologist, the ear mould producer, the teacher, the parent and the child with hearing disability. Attempts made in this regard in recent times through the Ministry of Welfare and with reference to computer programmes between Voice and Speech Systems (VSS), Bangalore and the All India Institute of Speech and Hearing (AIISH), Mysore are good examples of how useful such exchanges can be. Unfortunately professionals are often secretive and not willing to share information with others. They show jealousies and a lack of mutual respect. The Mass Screening by broadcast developed at AIISH, Mysore

for the Radio and by the AYJNHH, Bombay for T.V. do not seem to have been used as well as they could be. Infant screening procedures initiated at AIISH have not been continued and improved upon. Thus because one does not recognise the work of another the wheel gets re-invented. Attempts to produce battery and cord testers which is a simple way to identify hearing loss in children, and infant hearing screeners/testers are examples. They have been developed often but nobody has been able to distribute them widely.

Another disincentive to innovators is the fact that many professionals are unwilling to show concessions and make compromises while a new aid is being developed. Actually some of these needed compromises are real, meaning that they would affect performances, while some others are not. What an innovator or manufacturer would need is an honest trial of his product and a proper feed back, which would foster improvement. Then there are many professionals who do not take the effort to advise the end user — the client. The guidelines given by AIISH to clients regarding the maintenance of aids and therapy at home have proved to be beneficial and would underline the benefit of such exchange and training.

Many of the teachers of children with hearing disabilities are untrained. Even when trained, their training of necessity deals only briefly with the use of technology aids. Most of the schools where they teach are ill equipped and thus the teachers are not "technology oriented". In one instance, a teacher was awed by a group hearing aid system and would not use it. Many of these teachers are not aware of the use of hearing aids or of the need to check them every day for best results. They can be easily oriented: without such an orientation they do not make the best use of the aids.

The manufacturer/producer should also seek and encourage such an exchange of information. He should talk to the appropriate professional, discuss the needs of the user and then produce the aids. When the manufacturer tries this, he often gets conflicting views from the different professionals and ends up satisfying the biggest buyer among them even if it may not be valid. The hearing aid manufacturers seem to have concentrated more on the power of a hearing aid than on the frequency response and distortion, perhaps for this reason. Their largest buyers, the ENT specialists and teachers, have emphasised gain. The hearing aid is mentioned often in this paper because it provides a good example of the concepts involved and is one of the instruments indigenously produced, adapted and generally improved upon in India. Most producers or manufacturers are not professionals in the area of audiological aids. They may just borrow technology, sometimes only kits, and put aids together. They do not bother to improve the technology.

As a result of the lack of culture of technology, producers do not show a pride of product and tend to play foul with reference to quality control. This is one reason that the

imported aid is widely respected even at a higher cost. The cost of the Indian aid is also not all that low. The costs are high because the market does not match the great magnitude of need and is limited by purchase power. Overheads (including commissions) on each aid are high. The imported components, their custom and excise duties add to the cost. The quality is inconsistent and the aids are in need of repair often. Maintenance support is not adequate because the producers and sometimes even the importers of equipment remain purely as traders and do not develop any maintenance abilities or network. The manufacturers do not seem to worry too much about consumer education. The consumer is often illiterate or barely literate. He is not "technology conscious" and in many instances his contact with the professionals is short. Thus the aid is not fully utilised.

In this general milieu of a lack of the culture of technology it is difficult to envisage a small revolution brewing in terms of technology aids for disabled people. However pessimism is not a useful attitude. A proper drive to induce the culture of technology or to strengthen it where present will produce results. Several of the recent workshops on technology development, the success of the workshops on the development and maintenance of different aids, the successful completion of several multicentred projects such as the language and articulation tests done through the Regional Rehabilitation Training Centre (RRTC), Madras and the AYJNIHH, Bombay, the language analysis of aphasics done through AIISH, and the enthusiasm in technology that has been brought out by the invasion of the computers are some of the positive indicators that perhaps a change in climate has come about. We need to hasten the process and encourage the participation of all concerned: the professionals, the producers, the parents and the clients.

Other activities encouraging a culture of technology including the production and distribution of pamphlets, guides for teachers and parents of children with communication disabilities should be encouraged. Toys involving various levels of technological sophistication should be used in the class room and also perhaps kept in toy libraries to be borrowed and taken home so that the parents also get involved. The electronic and print media can be utilised to encourage a positive attitude of science and technology. It is obvious that public education, parent education, teacher/professional education and refresher education, and orientation education of allied professionals and other leaders of the community will be essential for technology applications to go on at full swing. A good example of this is this seminar being conducted by ActionAid — India.

It is important that aids are developed as and when possible as needed and that proper directories are available through a number of information centres. The lists should indicate where the aid is available, the cost of the aid, the prerequisites for its use, any alternatives that can be used, whom to contact for maintenance and any specific modification that may be felt necessary.

We ought to consider appropriate technology as that which can help an individual adequately overcome as many of his difficulties as possible within the money available to him. Generalisations are hard to make. Even when equipment has to be imported it is necessary to make sure that is tropicalised and can take highly fluctuating 220 volts - 50 Cycle current. Whatever is made for India at any cost must be made to last long. Cars and equipment are kept in use in India long after the original manufacturer stops their manufacture. The mechanics if permitted will in their own way repair and bring to working condition many items.

Attempts are also necessary to make able-bodied children and people aware of disabilities and handicaps and the different aids that are used. It is important because often technology aids are not used for fear of mockery, tampering and theft. When others are aware of the need of the aid to the individual it is hoped the aid would be received better by the peers. They may also be able to help the person with a disability to make the best use of the aid. Toys such as Barbie with a hearing aid, and other games can be developed with this in mind.

Sometimes technology aids may be too heavily emphasised. Some countries can afford to rely greatly on aids as seems to be the case in Japan. We ought to remind ourselves that excellent results had been achieved on occasion even without such technological support. Mabel Bell had acquired adequate speech and language even before her husband strove to develop a hearing aid for her. Helen Keller had no access to a technological aid. However aids speed up our efforts, make intervention more varied and more fun both for us and for the client. Some aids liberate our clients faster and make them more versatile, while others would help us quantify our activities better and thus improve the impact of such activities.

AIISH, Mysore has constantly attempted to develop many of these aids. AIISH is at present working on an S & T Mission Project on improved ear moulds. Another project to develop a telephone call signal is being considered. The Institute has been collaborating on and stimulating a computer base interface and programme to take up the function of several sophisticated aids for speech analysis and therapy, all rolled into one. The attempt now is to incorporate audiological tests and hearing aid analysis.

The AYJNIHH, Bombay has also shown similar interests. The National Institute of Mental Health and Neuro Sciences (NIMHANS) in Bangalore is taking up a Mission Project on developing ERA equipment. The RRTC, Madras has a project on solar batteries for hearing aids. In many of these the professionals are indicating their needs to the entrepreneurs who then produce aids. There is a constant interaction between the two. Often the entrepreneurs may take up mass production. Sometimes engineering students take up some aids as their project work. The different Indian Institutes of Technology and other apex engineering institutions in the country have

also been interested in developing aids for disabled people. Sometimes these institutions do not see the task as worthy of their talents. The manometer for an impedance bridge is a case in point. Almost every one says that its production is very simple but after many years we are still dependent on imported impedance bridges.

The various technology aids and processes that would help prevention, early identification, proper assessment, prosthetic support, other learning activities, employment, activities of daily living and entertainment are listed in the *Annexure*. Several aids which are common to those without disabilities and those with other kinds of disabilities are not included.

Often finances are indicated as the constraints to research activity in developing aids. Active workers however report that funds are usually not a problem for small, good pursuits. There is a great stimulation for the development of new technology aids. The Ministry of Welfare, Government of India holds an exhibition of these aids and gives awards every year. The Ministry provides grants to projects directly and channelises grants from other Government Departments and Ministries such as Science and Technology, Health, Labour, Woman and Child Welfare, along with grants from international agencies such as UNICEF, WHO and ILO. The Departments of Social Welfare in various states can support some research. There are many industries such as Tatas, Mafatlals, Titan, Brooke Bond and others, and banks which have some funds set apart for social service activities.

Many institutions — both Governmental and non-Governmental — can generate some funds for research and development of technology. In addition there are many international sources of funds such as ActionAid, HelpAge, German Leprosy Relief Association, AHRTAG, Royal Common Wealth Society, CARITAS, Nuffield Foundation, Christoffel Blinden Mission and OXFAM.

Public education and information dissemination is at the base of all rehabilitation activities beginning with prevention and early identification, all the way to vocational and social are rehabilitation. We have to use all the forms of public education and also all the modes including electronic media, print media and the oral person to person media. We also need to be innovative. All groups of children or people depicted anywhere in the media, for example at a playground or tourist spot or hotel dinner can include people with disabilities. Toy manufacturers and games designers can be persuaded to incorporate concepts of disabilities and disability information. Why should not Barbie wear a hearing aid or walk with crutches or with a white cane? T.V. and Radio can not only spread prevention messages but can also provide therapy guidelines along with demonstration of therapy techniques. In the same way public education can stimulate better social integration by presenting people with disabilities as human beings without any special negative or positive exaggeration. It is necessary to use all techniques available to lay the foundation for all aspects of rehabilitation including the use of technology aids. ■

ANNEXURE

TECHNOLOGY AIDS FOR COMMUNICATION DISABILITIES

I. Prevention

- Screening equipment to permit periodic checks, or self checks of hearing of children at risk, and workers at risk
- Guidance in scheduling of work for employees at risk
- Technology, and motivation and guidance in its use for ear protection
- Noise reduction by proper mounting, reduction of friction and vibration
- Noise attenuation by barriers, distancing, masking with music etc
- Care of the discharging ear
- Ear care tips for swimmers

II. Early Identification

- Techniques and tools such as toys and noise makers
- Crib-o-gram techniques
- Paedo audiometers
- Portable ERA
- Mass screening on T.V. and Radio and group screening tests
- Mobile test booths for hearing tests

III. Assessment

- Manometer for the impedance bridge
- ERA
- Development of standard tests for hearing, language and speech
- Stuttering duration, frequency and severity quantifiers
- Voice analysers
- Oral stimulators
- Laryngo graphs
- Speech analysis and synthesis

IV. Prosthetic Aids

- Improved hearing aids
- Ear mould equipment
- Ear moulds
- Ear protectors
- Cords, batteries and tubes connecting aid to mould
- Hearing aid test boxes
- Procedures for hearing aid quality control
- Improved group amplification systems
- Loop amplification system for group and individual use

- FM hearing aid systems
- SAFA devised by Kostic
- Vibrotactile sensors and vibrators
- Manuals of procedures for hearing aid selection, use, routine maintenance and repair
- Voice amplifiers
- Stethoscope amplifiers
- Communication boards
- Signal switches (light switching for word selection).
- Cleft palate prosthesis
- Blom-Singer prosthesis
- Speech synthesisers to speak out words selected by some means
- Cochlear implant prosthesis

V. Learning Aids

- Therapy programmes on computer
- DAF
- Metronome
- Self correction programmes
- Communication boards

VI. Living, Employment and Entertainment Aids

- Alarms
- Telephone/Door Bell Indicator
- Baby cry/Fire warners
- Tele-Typers
- Captioning of films and T.V. programmes
- Signed news
- Interpreter services
- Mobility assistance in terms of guidance-visual, signed auditory, and oral
- Transducers providing visual signals for equipment where signals are auditory

VII. Research Aids

- Voice and speech analysis including spectrograms
- Dichotic speech
- Compressed speech
- Physiology equipment



Technology for Mental Retardation

Dr. SHOBA SRINATH, Dr. Satish Chandra Girimaji
Dr. Shekher Seshadri

Mental retardation refers to significantly subaverage general intellectual functioning resulting in or associated with concurrent impairment in adaptive behavior manifested during the developmental period (American Association of Mental Retardation).

The prevalence of mental retardation in the general population is estimated to be approximately 2 percent, which amounts to a significantly large number of people. However, it is difficult to estimate the numbers of mildly retarded people as the difference between them and the general population is mostly in terms of academic performance rather than general performance.

Compared to other disabilities, mental handicap had received less attention in our country. There is a change now, with increasing involvement of Governmental and non-Governmental organisations in this area.

Technology as it pertains to mental retardation would mean the biotechnology for investigation and management, the designing of programmes and materials for training and manpower development. Many groups have worked on these areas, but without any significant networking of information. This paper attempts to review these few areas of technology.

Work with mentally handicapped individuals requires the involvement of a number of disciplines such as health, welfare, education, law and rehabilitation. The National Policy on Mental Handicap (1988) was the outcome of a meeting of experts from various disciplines. The objectives were to ensure availability and accessibility of basic care, to promote community participation and stimulate efforts towards self help in the families of mentally handicapped persons. Under the strategies for action, the urgent need to improve prenatal, natal and post natal care, emphasis on early identification and rehabilitation, special schools, pilot programmes and community participation have been highlighted.

The National Policy on Education (1986), outlines the steps for ensuring equal educational opportunities for disabled people. Integrated education of children with mental retardation is said to be most feasible in the pre-primary and primary levels. The methods needed to integrate these children at physical, social and academic levels are of relevance today.

The National Mental Health Programme (1982) envisages integration of basic mental health care including the care of mentally handicapped persons, with the existing systems of health care. For this integration, appropriate task oriented training for the existing cadres of health staff is being carried out with the National Institute of Mental Health and Neurosciences (NIMHANS) as the nodal agency.

In this paper, the available technology is reviewed under the subheadings of levels of prevention.

Primary Prevention

Primary Prevention is defined as "action which removes the possibility that a disease/disorder will occur". The goal of primary prevention is not merely the prevention of mortality, but more important, the prevention of morbidity, thus ensuring a well adjusted and useful life.

Health Promotion encompasses the general improvement of health and well being of the individual and the community. In relation to mental retardation, this means technology related to providing adequate nutrition, sanitary environment, personal hygiene, health education, marriage counselling, sex education and health services, all of which lead to improvement of standards of living. In India, the health care system through the primary health centres (PHC) and the Integrated Child Development Scheme (ICDS) are two programmes that reach the grass roots of the target population. The ICDS deals with primary prevention through the education of pregnant women and the work with pre-school children. The idea of including information on sex education and parenthood in high school curricula is another example of primary prevention. The technical aids that are needed for both the ICDS and school programmes are educational materials, charts, films and slides which exemplify these aspects of prevention. Building up public awareness about the common preventable causes and management of mental retardation, besides general health education are also important.

Health promotion, however, tends to be diffuse and may also be expensive. **Protecting specific populations** is considered to be more cost effective. The use of iodised salt in endemic areas to prevent mental retardation due to Hypothyroidism is one such example. The technology needed to iodise salt, transport and distribute it is available. Other examples are the use of Rubella Vaccine on a routine basis for adolescent girls, MMR immunisation, Rh screening of pregnant women and protection against Tetanus. The back up technology that is needed here would be the availability of vaccines, Rh typing facility and good distribution systems. Assessment forms have also been developed for measuring progress of labour to indicate when a woman in labour is to be referred to the PHC.

At risk infants like premature babies, low birth weight babies, babies with poor nutritional status and those with sensory handicaps comprise another group that needs specific protection. Technology for early identification and early stimulation/interventions is important in these cases. The National Institute for the Mentally Handicapped (NIMH), Secunderabad has done much work in this area.

Secondary Prevention

Secondary prevention may be defined as action which halts the progress of a disorder at its incipient stage and prevents complications. Since early identification and intervention for mentally handicapped children are very important, most of the advances in technology have been in these areas, as described below.

Biomedical - Investigative Technology

An etiological diagnosis of mental handicap can be obtained in 70 percent of the cases. Frequently used techniques are biochemical investigations such as aminoacid determination and mucopolysaccharide screen, prenatal infection screen such as TORCH (Toxoplasmosis, Rubella, Cytomegalovirus, Herpes), chromosomal analysis and radiological investigations such as CT Scan and magnetic resonance imaging. However, most of these facilities are available only in selected centres in metropolitan cities and are inaccessible to the large majority of people requiring them.

Programmes for Training Parents

The Nambikkai Nilayam, Vellore has a 3 month training programme for mentally handicapped children and their parents. At NIMHANS a 2 week period of stay for the children and parents is the mainstay of inpatient care. The refinement of the technology used for delivering and evaluating this service is part of an ongoing ICMR project at NIMHANS. At the All India Institute of Medical Sciences (AIIMS), a manual has been prepared for the training of parents in behavioural methods of management as part of an ICMR project. Home based programmes and parent training programmes have been developed by the NIMH, Secunderabad and by many non-governmental organisations.

The NIMH came into existence in February 1984 when it was registered as a society under the administrative control of Ministry of Welfare, Government of India. It is an apex body to develop models of habilitation and care for mentally handicapped persons which are applicable to various socio-cultural settings in the country. Its other objectives are to develop manpower, to conduct and co-ordinate research and to serve as a documentation and information centre.

The NIMH has developed guideline reading material, instruction booklets for parents and video films about various aspects of mental retardation.

An innovative programme called "Vojta Therapy" for training the parents in a particular method of stimulation is an ongoing project of the Thakur Hariprasad Institute at Secunderabad.

Technology for Man power Development

The NIMH conducts the Diploma course and the 3 year Bachelor's degree course in mental retardation. There are a number of short term courses like the refresher course,

training for Vocational Instructors and Counsellors, workshop for master trainers of the Regional Rehabilitation Training Centres and orientation courses for the staff of District Rehabilitation Centres (DRC). Training for manpower development in the field of mental retardation is also carried out by a number of non-governmental agencies such as the Central Institute of Mental Retardation, Trivandrum. Training courses conducted by the National Institute for Public Co-operation and Child Development (NIPCCD) for ICDS functionaries and by NIMHANS for PHC staff among others, provide exposure to mental retardation as part of their curriculum.

Aids for Training

The NIMH has published a significant number of training aids such as manuals for guidance counsellors, for psychologists, for multipurpose and village rehabilitation workers. A directory of institutions providing services for mentally handicapped persons in the country has been compiled. There are also booklets on how to organise a special school and to set up an opportunity section in a regular school. The NIMHANS manuals for PHC staff include chapters on mental retardation.

Integrated Education for the Disabled (IED)

Integration of mentally handicapped children has been only at the preprimary and primary levels. The reason is that as the child goes to a higher class he has difficulty in coping with concepts which are complex, unlike an orthopaedically disabled child with normal intelligence. The most often used method of integration is to have the mentally handicapped children in a different class room in the regular school, with opportunities for all the children to be together at break times, games, assembly and so on. The various teaching aids and materials needed for pre-primary and primary school children including charts, flash cards etc. are not easily available or accessible. It is necessary to set up a central library facility to pool these materials and resources together.

Tertiary Prevention

Tertiary prevention refers to disability limitation and habilitation. Prevocational and vocational training contribute greatly towards integration of disabled people into the mainstream, for which a network of rehabilitation and vocational training centres are necessary. Currently, most of this work is being done by NGOs. The vocational rehabilitation centres under the Government of India cater to only those whose intelligence quotient is above 50. It is obvious that mentally handicapped persons cannot be habilitated in all areas, but more of them may be helped if small scale industries and other such organisations in the private sector can play an active role.

The area of special education requires a compilation of available training materials, the bulk manufacture of these

materials, and manpower development, along with increased availability of funds.

Technology for Assessment

Some screening instruments used in epidemiological studies on mental illness and others have questions relating to mental retardation. NIMH has co-ordinated a study for the development of a proforma for mental retardation, which is quite comprehensive. Many tests for intelligence and language are available, but there are problems of modifications and standardisation. The All India Institute of Speech and Hearing (AIISH), Mysore and the Ali Yavar Jung National Institute for Hearing Handicapped (AYJNHH) have been involved in the development of appropriate test materials. The modified versions of the Portage schedule, the Bayley scales, the Denver Development Schedule and Vineland Social Maturity Scale are being used in India.

Issues in Technology

Prioritisation

The need of the hour and the funds available are likely to dictate what should be the priority, as in the case of the decision to stop broad screening for metabolic disorders in newborn infants in many centres. Today, only a few specific conditions such as hypothyroidism, PKU, or galactosemia are being screened for. However, in endemic areas, routine neonatal hypothyroid screen is required to be done for all newborn infants. The priority will also vary depending on the organisations involved. For example, the department of health may prioritise early identification, while the department of education may stress mass education. In another example, while genetic counselling centres do excellent work, it may be more useful to prioritise areas of prenatal and natal trauma, which play a larger role in the causation of mental retardation than genetic factors.

Accessibility

In some instances, technology may be available, but is not accessible to all. There may be a good tool for screening, but if it is not translated to the local language, its utility is limited. There are also toys, play materials and teaching aids which are not accessible to the most needy for various reasons.

Appropriateness

The inappropriate use of materials and aids such as the use of an English cassette in a non-English speaking rural

setting or use of home based interventions for children whose parents are not regularly available at home, can limit the utility of the intervention.

Funding

Much of the work in this field is carried out by voluntary efforts and donations. Grants are also given by the ministries of Social Welfare, Health and Education to voluntary agencies providing services for mentally handicapped persons. Besides governmental agencies, funding organisations like WHO, UNICEF, ICMR, ActionAid, OXFAM and the National Institute on Disability Research and Rehabilitation (NIDRR) among others are also funding projects which include services for mentally handicapped persons. The NGOs spend a large part of their time and efforts in raising funds. To establish an infrastructure in the country, replication of successful models should be encouraged. However, innovation should not be curtailed because different aspects of mental retardation may have different requirements. Funding should also be oriented to family and community based projects in rural areas and urban slums.

Research Linkage

In discussing research demands, Stark et al (1986) have pointed out that human services face barriers such as insufficient financing, political influences, too many individuals to serve, not enough time to accomplish what is expected, lack of adequately trained staff and short term results with a lack of generalisation across settings. Menolaseino and Stark (1990), in a paper on "Research versus Advocacy in the Allocation of Resources", conclude that allocation of resources should take into consideration the needs of the community, with reference to established scientific findings. The researcher should in turn, consider the clients' needs and diffuse innovations to clients, while also being ready to reorganise those needs and adapt innovations.

To conclude, some of the areas to be highlighted are development of a data base of available technology for mental retardation, further allocation of resources to utilise already established technology, encouragement of innovations though chances of failure may be high in some instances, and possible separate allocation of funds for mental retardation by funding organisations. ■

Discussions and Summing Up

DR. C. M. FRANCIS

1. The issue of information gathering and dissemination came up repeatedly in the discussions. Information on various aspects of disability and rehabilitation, including technology, is important for creating awareness. Such information would need to be collected and collated not only from India, but from the neighbouring countries and other developing countries as well. There should also be information on availability of funds in the Government and non-governmental sectors, along with the policies, priorities and eligibility criteria of funding organisations.

Regarding information gathering in the area of rehabilitation, a suggestion that came up was the creation of problem banks to generate information and solutions to specific requirements and problems of different people/institutions in this area. This could be initiated by any organisation, for example, through the newsletter of ActionAid Disability Division.

2. Promotion of widespread acceptance of disabled people in their communities and society was felt to be important. It is suggested that children and adults with disabilities be shown in their natural settings, as people without disabilities are shown, by the communication media and by those involved in the field of rehabilitation.
3. Consumer awakening and action with regard to technology in rehabilitation is to be encouraged, to promote better and improved technology in the service of disabled people. Along with this, consumer guidance regarding availability of developed technology also needs to be taken into account.
4. Shortage of trained personnel is a continuing problem in the field of rehabilitation. Issues of whom to train, how to train and where to train need to be addressed. Funding organisations could also play a role in supporting training programmes.
5. In many instances, technology is developed and promoted at great cost, but the benefits are nullified because of lack of maintenance and improper utilisation. The field of bio-medical engineering needs to be promoted, in the service of technology for disabled people.
6. Technology for prevention of disabilities is of importance and requires to be promoted at the Governmental and non-governmental levels.
7. Research in the field of rehabilitation is another area of importance. Applied research is what needs to be

stressed, along with its interface with the areas of service and training.

8. In view of the magnitude of the problem, meagre financial resources and lack of adequate trained manpower, it is suggested that priorities may be ordered and attended to in their order of importance.
9. Preparation and wide dissemination of available training materials, including translation of these materials into local languages is suggested, though this may not be an easy task.
10. For the purpose of mobilising resources, planning interventions and fixing priorities, it would be necessary to know the exact magnitude of the problem to be addressed. Surveys are therefore important to get a clear picture of the numbers, along with the degrees of severity of disabilities and handicaps. The society's attitudes towards disabled people need to be studied, to develop strategies to promote greater acceptance of disabled people.
11. Research on appropriate materials in the area of technology is yet another area of concern. It had been shared during the day's deliberations that work on PVC and polyurethane in prosthetics and orthotics had been going on in ALIMCO and in other private organisations, apart from the work on the Jaipur foot. Further research on development of appropriate materials needs to be taken up.
12. The issue of what constitutes appropriate technology was the subject of discussion. Appropriate technology is not primitive, nor is high technology costly, in all instances. Appropriate technology needs to be considered as that which is appropriate to the given conditions and circumstances.
13. Participatory decision making in the area of technology in rehabilitation is also necessary, in that funding organisations and implementing agencies need to work together, taking into consideration the actual needs of the beneficiaries.
14. Another theme that had come up repeatedly was the need for a multi-disciplinary approach with regard to technology development. It is suggested that a closer interaction and dialogue between the rehabilitation institutions, universities, manufacturers, industries, non-governmental organisations and funding organisations be promoted, again with the needs of the end user in mind.

15. The issue of flexibility of systems with regard to donor agencies was brought up. Many donor agencies tend to be rigid in their requirements and soft parameters may not be acceptable. This approach, however, tends to discourage innovativeness in attempts to improve the quality of services rendered:

16. In conclusion, the chairperson pointed out that specific action plans had deliberately not been formulated, so that individual organisations may do so and continue to share and disseminate information on their work at the field level. ■

Glimpses of the proceedings

